

Community-Based Participatory Research as a Tool to Advance Environmental Health Sciences

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The past two decades have witnessed a rapid proliferation of community-based participatory research (CBPR) projects. CBPR methodology presents an alternative to traditional population-based biomedical research practices by encouraging active and equal partnerships between community members and academic investigators. The National Institute of Environmental Health Sciences (NIEHS), the premier biomedical research facility for environmental health, is a leader in promoting the use of CBPR in instances where community–university partnerships serve to advance our understanding of environmentally related disease. In this article, the authors highlight six key principles of CBPR and describe how these principles are met within specific NIEHS-supported research investigations. These projects demonstrate that community-based participatory research can be an effective tool to enhance our knowledge of the causes and mechanisms of disorders having an environmental etiology, reduce adverse health outcomes through innovative intervention strategies and policy change, and address the environmental health concerns of community residents. *Key words:* community-based participatory research, translational research, environmental health sciences, environmental justice, community outreach, health disparities, children's health. *Environ Health Perspect* 110(suppl 2):155–159 (2002). <http://ehpnet1.niehs.nih.gov/docs/2002/suppl-2/155-159ofallon/abstract.html>

NIEHS Mission: Disease Prevention

Disease prevention is the most effective form of healthcare because it protects people from illness, and as a result, saves money, minimizes suffering and improves the quality of life of the American public (1–9). To prevent disease effectively we must first understand fully the cause of an illness and change the conditions that permit it to occur. However, people are exposed to myriad environmental factors, physical as well as social, on a daily basis that could adversely affect their health. In addition, everyone has different genetic predispositions to disease and different probabilities for exposure. At the National Institute of Environmental Health Sciences (NIEHS), researchers strive to understand disease end points that result from environmental exposures by approaching health as an integrated response of all organ systems over time to the environment.

Unique within the National Institutes of Health, NIEHS focuses on the prevention of disease rather than on the treatment of illnesses. To guide research efforts at NIEHS, human health is conceived as the interaction of age (time and/or duration of exposure), susceptibility (genetics), and exposure (physical or social). Researchers apply this model to the study of health outcomes (e.g., cancer, birth defects, asthma/respiratory diseases, infertility, autoimmune diseases, neurodegenerative and developmental disorders), environmental exposures (e.g., pesticides, heavy metals, radiation), and the early molecular events that initiate the disease process (e.g., DNA damage, apoptosis). Much is

already known about these three components individually. However, relatively little is known about the initial “triggers” that start the disease process. Without understanding this, it is difficult to intervene to prevent disease.

While preventive research can enhance our understanding of the early steps of the disease process, the Institute also recognizes the necessity of addressing environmental health concerns of community members while research is ongoing (10). In response to these needs, NIEHS established innovative initiatives that begin to bridge the gap between researchers and community residents. NIEHS envisioned that the partnership of these two groups would address community environmental health issues, while enhancing basic etiologic and exposure assessment research as well as facilitating the development of novel approaches to prevention research.

Community-Based Participatory Research at NIEHS

Guided by renewed interest in community-based participatory approaches to public health (11–17), NIEHS began applying these methodologies to preventive research to better meet the immediate environmental health needs of affected communities, especially socioeconomically and medically disadvantaged populations. NIEHS initiated a Translational Research Program in the early 1990s to link researchers and community residents by encouraging collaborative research projects. The purpose of the program is to refine intervention methods,

provide exposure assessment data, study environmental disease etiology, and facilitate the conversion of findings from basic, clinical or epidemiological environmental health science research into information, resources, or tools that can be applied by healthcare providers and community residents to improve public health outcomes in at-risk neighborhoods. Community-based participatory research (CBPR), which the Institute defines as “a methodology that promotes active community involvement in the processes that shape research and intervention strategies, as well as in the conduct of research studies” (11), constitutes a large part of the Translational Research Program.

Six Principles of CBPR

With the growing use of CBPR, there is a corresponding need for an agreed upon set of guiding principles for conducting CBPR (12). On the basis of prior investigations (13–20) and interactions with practitioners (11), NIEHS endorses the following principles for effective CBPR:

Promotes active collaboration and participation at every stage of research (13–15). CBPR fosters equal participation from all partners. It provides all participants with an equal sense of ownership over the research and the outcomes.

Prominent initiatives within the NIEHS Translational Research Program that highlight this feature include Environmental Justice: Partnerships for Communication, Community-Based Participatory Research, and Centers for Children's Environmental Health and Disease Prevention Research (21,22). In these programs, all projects demonstrate collaboration between environmental health scientists and members of community organizations.

An example of active community participation in the research process within the NIEHS CBPR initiative is the project Preventing Agricultural Chemical Exposure

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(PACE) in North Carolina (23). The academic researchers in this project work with two populations—migrant farmworkers and tobacco growers. Recognizing that a partnership with a community-based organization does not always lead to the greatest amount of community participation and that there exist different levels of participation, they use five modes of interaction to assure that the voice of the community partner is heard: *a*) partnership with a community-based organization; *b*) a project advisory committee; *c*) community forums for residents more active in the research process; *d*) public presentations for less active residents; and *e*) formative data collection. This last method consists of interviews to help investigators learn about community member perceptions of environmental health concerns and gain insight into social networks. Issues that had to be addressed to assure community participation included transportation and meeting times. On occasion, researchers would provide transportation to residents and convene community forums at times convenient to the population.

On the basis of community interaction, researchers developed a two-phase intervention to reduce farmworker exposure to harmful agricultural chemicals. In the first stage, field safety promoters received training in agricultural safety and health to serve as a resource to other workers. In the second stage, project staff and field safety promoters presented a Worker Protection Standard (WPS)-certified training course. After completing a post-test evaluation, it was evident that many farmworkers still did not receive pesticide training and few were aware of the ways in which they could be exposed. Consequently, researchers modified the intervention slightly by switching the order of the phases to improve worker awareness of health risks from pesticide exposure (24). The success of the community–university partnership has led to researchers receiving funding from the North Carolina Department of Agriculture and Consumer Services and two chemical producers, Syngenta and Aventis CropScience, to develop a Spanish language training video on pesticide safety for farmworkers (25).

Fosters co-learning (13,14,16,20). CBPR provides an environment in which both community residents and researchers contribute their respective expertise and where partners learn from one another. Community members acquire new skills in conducting research, and researchers learn about community networks and concerns—information that can be used to inform hypothesis generation and data collection.

The Southeast Halifax project, a partnership among the University of North

Carolina at Chapel Hill, Concerned Citizens of Tillery (North Carolina), and North Carolina Student Rural Health Coalition (healthcare provider), demonstrates how community residents and investigators learn from one another throughout the research process. In this project, academic researchers work with residents from a rural town in eastern North Carolina to determine the extent of disproportionate exposure to hazardous substances from intensive livestock operations surrounding predominantly African American and poor rural communities and the resultant health impact upon residents. The first question addressed was whether a quantifiable environmental injustice existed. Residents helped researchers collect population and swine operation data, analyze it, and later publish their findings (26). Results demonstrated that corporate hog operations are more concentrated in poor non-White areas than those run by independent farmers (26). The next question addressed the potentially harmful effect of intensive livestock operations on the health of surrounding communities. Previous work had demonstrated adverse health effects of intensive livestock operations on workers. Hence, researchers and community members postulated that those communities located within 2 miles of a hog farm could suffer adverse health outcomes. In collaboration with community members, researchers designed a questionnaire to collect data within affected communities. Results from the investigation showed an increase in reported headaches, runny nose, sore throat, excessive coughing, diarrhea, and burning eyes compared to residents of communities not located near intensive livestock operations (27,28). Ongoing collaborative work seeks to explore further the relationship of such symptoms to groundwater and air contaminants associated with livestock operations. Residents and departments of health in other states in the United States are using the methods and results of this research as important factors in considering the formulation of stronger laws and regulations to protect them from harmful exposures due to intensive livestock operations.

Ensures projects are community-driven (14,15,20). Research questions in CBPR projects are guided by the environmental health issues or concerns of community members.

NIEHS recognizes that for research and prevention/intervention strategies to be successful, they must address the concerns of the community residents. Therefore, all CBPR projects supported by the NIEHS build upon needs identified by the community. An additional impetus for Translational Research program initiatives at the NIEHS is the need for community residents to acquire scientific

knowledge about environmental exposures in their area that may be used to inform policy and regulatory decisions.

West Harlem Environmental ACTION, Inc. (WEACT), is a model of how the community has been a driving force behind each stage of the research process. Through a successful collaboration with the Columbia University, Joseph L. Mailman School of Public Health, community members help design, implement, and participate in multiple research projects. This community–university partnership has been successful in obtaining support via numerous means, including NIEHS Environmental Justice, Community-Based Prevention/Intervention Research, Environmental Health Science Core Centers, and Children's Centers programs. One joint study demonstrated a correlation between high concentrations of particulate matter ($\geq 2.5 \mu\text{m}$) and diesel exhaust particles on the sidewalks in Harlem in New York City and local diesel traffic density (29). This issue was of growing concern to residents because of the high asthma rates in children. Residents used data collected from the study to inform city officials of the potential health risk. As a result, officials closed a bus depot in close proximity to an elementary school. In a similar collaborative study, researchers and community members were able to demonstrate that not only are adolescents exposed to diesel exhaust but that they are suffering from potential lung impairment (30). Researchers at Columbia University are also working with community residents on a Healthy Home, Healthy Child campaign to enable mothers to protect their children from known environmental health risks for asthma, delays in growth and development, and cancer (31).

Disseminates results in useful terms (13). Upon completion of CBPR projects, results are communicated to all partners in culturally appropriate, respectful, and understandable terms.

A primary goal of the Translational Research Program at NIEHS is to foster and enhance communication among community members and researchers to more effectively reduce health risks. To this end, NIEHS encourages the development of appropriate education and communication modules.

Researchers at Oregon Health Sciences University in Portland, Oregon, work with families of farmworkers throughout Oregon to break take-home pathways for pesticide exposure in children. In collaboration with the Latino agricultural community and other local stakeholders, researchers are assessing household conditions and biomarkers for pesticide exposure, developing methods to assess neurobehavioral function in non-English speaking children, and

developing culturally appropriate education materials (32).

Investigators in this project use several mechanisms to communicate findings to community members in a culturally relevant and understandable way. The mobile nature of the affected community presents a challenge to disseminating findings to everyone. Community meetings and sharing of collected data (e.g., biomarkers and neurobehavior test results) with families are two effective ways in which investigators are communicating research results to participating community members. These efforts provide residents with information on research status, implications for their health, and a forum for asking additional questions. Researchers also developed an educational video based on the results of focus group discussions on farmworkers' beliefs and practices. This video is used to educate families on how they can minimize contact with pesticides in and out of the home.

Ensures research and intervention strategies are culturally appropriate (13–15,19). With active participation of community residents from the beginning, research and intervention strategies are more likely to be based in the cultural context of the community in which such work is intended to benefit.

The Tribal Efforts Against Lead (TEAL) project in northeast Oklahoma demonstrates how CBPR assures that research and intervention strategies are appropriate to the affected community. With residents involved in the research process from the beginning through a community advisory board, academic scientists were assured that their efforts would be responsive to the needs and concerns of the residents. In designing and conducting intervention research, scientists worked with the Society of Clan Mothers and Fathers. This community group selected intervention strategies, and in collaboration with researchers, developed educational materials and outreach activities to address childhood lead poisoning.

Involvement of the Clan Mothers and Fathers was advantageous to the research effort because they were part of the community and had access to the social circles that the scientists would not have been able to work with otherwise. Their knowledge of local events contributed to the effectiveness of the intervention because Clan Mothers and Fathers were able to reach a wider audience. Preliminary data show that there has been a statistically significant drop in the child blood lead levels. In addition, this collaborative research effort has had an impact on local and state policies. For example, community residents were able to use information collected in this project to persuade City of Miami officials to explore regulation of

chat (tailing piles left over from mining operations) in construction. In addition, research findings from this project helped to convince a Governor's Task Force to support continued soil remediation (33). These outcomes demonstrate how results from joint community–university research projects can impact regulatory and policy decisions.

Defines community as a unit of identity. One of the greatest challenges to CBPR is defining “community” because of its many socially constructed dimensions. For example, community could be defined as residents within a town, an ethnic population, a set of workers, or apartment building residents. Units of identity, such as family membership, social networks, or neighborhoods are created and recreated through social interactions (13). Because of its dynamic and diverse nature, no one definition of community can be applied to every situation. Therefore, it is important that community ultimately be defined by the people whose health is most likely to be affected by the research (17).

NIEHS Translational Research programs promote collaborations among academic scientists and community partners from underserved communities. In the case of these projects, community is typically characterized by a sense of identification and emotional connection to other members through common interests and a commitment to address shared concerns, such as harmful environmental exposures or environmental injustice.

NIEHS-supported projects have been successful in addressing the concerns of different communities through a variety of means. For example, the Southeast Halifax project identified a subset of a town in rural eastern North Carolina. In this case, community was a group that recognized themselves as the Concerned Citizens of Tillery, whose desire was to see the issue of intensive livestock operations addressed. The community was well defined prior to the researchers' involvement, thereby facilitating a partnership, because both groups had shared goals and synergistic expertise. Because Concerned Citizens of Tillery knew what they wanted, researchers were able to address their identified concerns.

The PACE project works with a more fluid community of farmworkers, many of whom originate from different countries (Mexico, Guatemala, Puerto Rico, and Honduras). Although an organization exists to organize these workers, researchers recognized that partnering solely with the community organization would not provide them with the necessary level of participation. Consequently, researchers reached out to the larger affected community to ensure greater participation so that the project and

intervention could be designed in a culturally appropriate manner. In the end, this project nurtured a sense of community by engaging the farmworkers collectively.

The TEAL project has been successful because it established a Community Advisory Board that brings together representatives from the many Native American Tribes living in Ottawa County, Oklahoma, to address the issue of lead exposure in a coordinated manner. The advisory board provided guidance and direction to the researchers. More than that, the board facilitated investigators' interactions with the affected communities by helping investigators interpret data and distribute information to the communities, selecting members to become Clan Mothers and Clan Fathers, and developing and conducting the training. In this project, the advisory board represented the community with a shared interest in lead exposure.

CBPR Benefits Scientists and Communities

The challenges of implementing and supporting CBPR are well documented (11,13,34). Chief among these challenges is ensuring participation on the part of universities, health departments, funding agencies, and federal institutions because CBPR may not necessarily fit within their research or funding paradigm, and the benefits of investing time and money into CBPR may not be immediately clear to these institutions. Through its Translational Research Program, NIEHS has addressed this issue by elucidating the above principles and benefits of CBPR to universities, state and local health departments, funding agencies, and federal institutions.

Outcomes from CBPR projects demonstrate a number of benefits of this methodology for both academic researchers and community members (11,13). These benefits depend upon the strength of communication and cultural understanding among all partners. Although communication is not the only aspect crucial to successful CBPR, without it the benefits of CBPR will not be realized. As shown in Figure 1, communication must remain a constant element throughout the entire spectrum of community–university interaction. On the basis of previous work (11,13) and the positive outcomes from the five highlighted examples in this article, NIEHS emphasizes the following benefits of CBPR for both researchers and community members:

Trust between researchers and community. By involving community members in every stage of the research process and communicating findings to them in culturally appropriate and understandable terms, CBPR

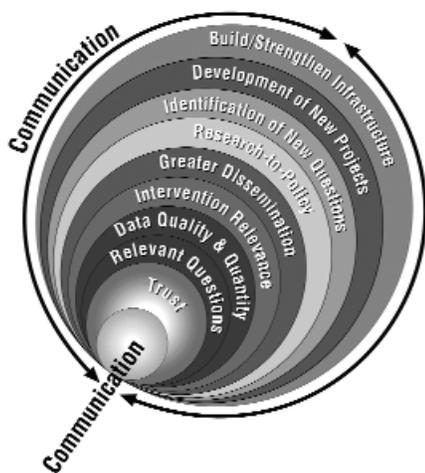


Figure 1. This figure illustrates the importance of communication for achieving benefits from CBPR projects. These benefits begin with and are maintained by honest communication among all partners in the research project. Each benefit is enhanced by the preceding benefit. That is, greater trust translates into increased relevance of questions, which assures better quality data, and so on.

enhances trust between the researcher and the community. Historically, communities have often been seen as cohorts rather than full partners in the research process (11,16–18). Communities often did not receive information from investigators regarding research outcomes and seldom perceived any benefit from having participated in research projects. As a result, community residents have been hesitant to participate in such work with scientists. Active participation by all partners in CBPR counters this skepticism and thereby increases the likelihood for success of a given research project.

Increased relevance of research question. Community participation ensures that the research question under investigation is relevant to the needs and concerns of both the researchers and affected residents. Without a mutually beneficial research question, the potential impact of the project on public health will be lessened.

Increased quantity and quality of data collection. When trust is established among partners in a research project and the question is of concern to individuals within the community, more residents participate. This positive relationship enhances recruitment and retention, which, in turn, improves data quality.

Increased use and relevance of data. When research questions are based on issues of importance to both researchers and the identified community, the data collected are more likely to be applicable to the scientific hypothesis under study. Moreover, data are

useful to the community in addressing their primary concerns.

Increased dissemination. Community, in the context of CBPR, is a socially constructed network. If the community possesses a sense of active participation in a research project, they are more willing to assist in dissemination of the findings. This effort enables research results to reach a wider audience of both scientists and lay public.

Translates research into policy. If research questions are based on community concerns and quality data are collected, there is a significantly greater likelihood that research findings can ultimately be used to impact policy to benefit the health of the affected community. In other words, the knowledge gained through research benefits the overall health status of the community. Moreover, such a change in policy and the resulting improvement in population health, even if on a small scale, often serves to highlight the researchers' accomplishments to academic institutions and funding agencies.

Emergence of new research questions. Through community involvement new ideas are developed and other questions that were not considered at the beginning of the project are highlighted. As trust increases among researchers and community members, richer dialogue occurs that can open up new research aims.

Extend research and intervention beyond specific project. Development of a strong, trusting relationship enables a community–university partnership to expand its work into multiple future research projects. Such collaborations are often successful in obtaining numerous means of support and in leveraging resources and expertise to create synergistic outcomes.

Builds infrastructure and sustainability. Partnering with community members from the beginning of the research process is an investment in the community. Residents acquire new skills and become leaders within the community, which leads to sustainability of a project. In turn, this infrastructure development leads to more cost effective research and permits scientists to carry out research projects of longer duration and larger scale.

Conclusion

NIEHS is a leader in biomedical and behavioral prevention research. As part of its mission, NIEHS has developed a successful, innovative translational research program to address the environmental health concerns of socioeconomically disadvantaged communities throughout the United States. The success of its initiatives has been due, in part, to the Institute's

encouragement of community–university partnerships that adhere to the six principles highlighted in this article. The projects discussed and the benefits enumerated demonstrate how CBPR can be an effective tool to enhance our knowledge of the causes and mechanisms of disorders having an environmental etiology and also to reduce adverse health outcomes by affecting policy change and developing culturally appropriate intervention strategies.

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